COMMUNICATING TOGETHER

published by Sharing to Learn

AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 15, NO. 1/MARCH 1998

ISSN 0822-0638

ComTog OnLine http://www.ahs.uwo.ca/orcn/assoc/comtog

EDITORIAL

Sexuality

PETER LINDSAY
& NOLA MILLIN

Six years ago, we introduced the first issue of **Communicating Together** with sexuality as the theme with the statement:

> **"Except for communication, what could be closer to our essence as human beings?"**

We haven't changed our minds. In spite of it being close to our essence, we as humans have a great deal of difficulty talking about it. We don't have terms we are comfortable using. We consider our sexuality as probably the most private part of ourselves, the most difficult to disclose. Our most intimate moments are our most private moments. In spite of our discomfort, talk about it we must. We must provide those who cannot speak appropriate opportunities to learn about their own sexuality and needs for intimacy. It must be dignified and respectful but it must be done.

The topic is so enormous. Once again however, when we faced the quandary over what issues we should talk about, we relied on letting our writers make the choice. We are very pleased with what the people we asked had to share. We found the mix of consumer views and the views of persons working in the field particularly informative.

Anne Abbott in her feature on *Sex and the Woman with Disabilities* is probably at one extreme in terms of the opportunities she has had. She has experienced the joys of intimacy in marriage and is looking forward to eventually experiencing perhaps an even more intimate relationship, that of motherhood. It is interesting to note that Anne took advantage of modern technology to meet and court her future husband. She met him on an electronic bulletin board system. What a wonderful example of how new communication technology can be used to provide opportunities to satisfy such fundamental, intimate and personal needs.

The contribution from Erica Simpson, a new author for us, is also very moving. It provides a compelling reminder that under the skin, we are all basically the same. We have the same hopes, the same fears and the same needs. The decisions we make are likely to be the same. They are based on our humanity, not whether or not our arms and legs work properly.

Rick Enright provides a perspective from a dedicated professional working in the field. Rick reminds us that persons with physical disabilities typically do not have opportunities to learn about sexuality let alone experience it. Typically they are not able to engage in the activities that preoccupy most teenagers — the give and take banter that most young people experiment with when they are learning about the opposite sex. Rick points to the central role of communication in this process and hence the special problems individuals with communication impairments will have in availing themselves of this opportunity to learn. Rick also emphasizes how crucial it is for care givers, professionals and parents to provide information about sexuality and human relations.

Tim Kinney introduces the important notion of *intimacy* into the discussion of sexuality. Intimacy is the more all-encompassing term. It focuses our attention on the importance of having deep trusting relationships whether or not they involve physical intimacy. According to Tim's research, persons with physical disabilities feel that experiencing intimacy is a central component of their perceived quality of life.

Cory Silverberg comes to the topic from a very novel perspective — that of a "sex-toy" salesman. In fact Cory has dedicated a good part of his professional life developing and disseminating sexual devices that help persons with physical disabilities to satisfy their sexual needs. Cory makes the very important point that when it comes to sexuality, each of us is our own best expert.

In *As Communication Changes*, Audrey McGee and Steven Hanlon provide perspectives from people living in an institution. Audrey provides a moving ode to her love for her late husband. Steven talks about the importance of continued opportunities for intimacy and touching both with his wife and others in the institution. He points out that the touching does not have to be sexual to be satisfying. As Alda Steprans suggests, it is absolutely crucial that chronic care institutions provide opportunities to the residents for maintaining intimacy as well as sexual activities if they wish to do so.

Geb Verburg in his "Coming out" *Context*, provides his usual provocative slant on the issue. As Geb points out, lesbians and gays who also have profound physical and communication disabilities would seem to have almost insurmountable obstacles to having their sexual orientation accepted. He also addresses the particular difficulties that these individuals have in gaining accurate information about their sexuality or

in finding anyone with whom they can discuss it. If they are using an alternative graphics communication system, they may have a few standard sexual terms that they can use. They are unlikely to have terms related to gay or lesbian sex.

Geb proposes a rather novel solution. He suggests that the Internet could be used as a vehicle for sharing life stories written by persons with physical and communication disabilities. This could be taken a step further. Perhaps the discussion groups that can be set up on most bulletin board systems could be used by persons with communication disabilities to share their experiences, their fears and knowledge with one another. Maybe it would serve as the Mall experience that is so popular with typical teenagers.

This is the first issue with a *Book Reviews* section. The need for information is so great in this area that we thought we should suggest a few books that are useful. *See What We Say*, reviewed by Shirley McNaughton, is an excellent resource for anyone involved with individuals with significant speech impairments. In fact, it was written by Barbara Collier, the reviewer of the second book — *End the Silence.* This latter book is an invaluable resource for dealing with an increasingly pernicious problem for men and women with significant communication impairments — the problem of sexual abuse and sexual assault.

The final piece in this issue is "Society's Compass" in *Paul's Place*. Paul reminds us not to be too driven or blinded by whatever society proposes as the appropriate current view of sexuality. He suggests that we need also to consider the more enduring view based on spiritual rather than secular principles.

In 1992, our editorial in the issue on sexuality opened with the declaration of *Rights Concerning Human Sexuality* proposed by Beatrice Wright. According to Wright, the first right is:

> **"the right to be informed about the biological and social-psychological facts of sexual behaviour."** (Wright, 1983, p. 257, from Chigier, 1992)

This plea for education and information is probably the least controversial of the rights encoded by Beatrice Wright. But surely it is a minimal prerequisite. How can individuals who are unable to communicate through speech make informed choices about expressing their own needs for sexuality and intimacy if they do not have basic information about human responses and needs in this area? Have we made progress in those six years towards accomplishing this basic need for education and information? If we are to judge by the writers in this issue, apparently not.

From Nola Millin

Since I didn't write an article for this issue, Peter & Shirley asked me to add my thoughts to the editorial. Like Peter, I feel the topic of sexuality is enormous. Sexuality covers such a wide spectrum that it is difficult to know where to begin. Thinking about it, I felt compelled to share how I learned about sex and my sexuality.

Being a child with a speech impairment, it was impossible for me to ask all the questions that kids ask. Fortunately, my mom realized that I might be wondering about things. One of the neighbours was pregnant and I was age six. My mom knew I probably wanted to know how and why the baby was in the woman's "tummy." In a simple way, my mom explained the "facts of life." My mom was a firm believer in using correct terminology. She didn't believe in calling various body parts by cute names. Sex wasn't a taboo subject in the privacy of our home. I felt free to ask her questions. As I matured, she explained things in more details. When I reached puberty, my mom went to the library to obtain books for me just to assure me that what was happening to me, physically and emotionally, was all natural. My mom even told me about masturbation because she realized penned up desires needed to be released. I'm very thankful for my mom's openness and willingness to recognize that I am a sexual being.

Now that I'm an adult, I'm comfortable about my own sexuality. In many ways, I can identify with Anne Abbott. I grew up believing I would get married and have kids. I never doubted it. I haven't been as fortunate as Anne at finding a husband, though I have had boyfriends. I don't know whether or not I will find that special someone. What I'm more aware of these days is how important touch is, and how uncomfortable people can be touching a disabled person. Some people treat us like we have some foreign disease! I'm not talking about the intimate touches between lovers; I'm referring to the "pat on the back" or the embrace between friends. I'm very fortunate because I do receive hugs but I know disabled people who don't. To me, a hug, a touch on a shoulder or on the arm can speak volumes. I think it adds to our over all sexuality. It says that the other person cares and thinks we are worthwhile.

In my mind, sexuality isn't just about sex. It's about who we are and what makes us tick. I hope that we who have disabilities will be given every opportunity to learn about our sexuality. Just because we use an AAC device and have physical limitations doesn't mean our sexuality is any different! I'm certainly not asexual!

(See page 6 for references) §

Sex and the Woman with Disabilities.

ANNE ABBOTT

Anne Abbott

Artist and freelance writer Anne Abbott has lived with cerebral palsy since birth. She has written several articles for ***Abilities*** *magazine, and recently has become president of the Greater Toronto Area Augmentative and Alternative Communication Advocacy Group. She lives in Toronto with her husband Rob and her cat Dandylion.*

Everything seemed so simple when I was a child. Sure I had cerebral palsy and had to have assistance with all of my daily needs. But I also had a family that loved me, supported me and tried their best to give me as normal a life as possible. With them behind me I felt as if I could do anything or become anybody I wanted. When I told them that I wanted to be a doctor or a nurse or an actress when I grew up, nobody made fun of my dreams or said that they were impossible. When I told them that some day I wanted to be a wife and mother they would say: "That's nice, dear, I am sure that will happen one day for you if you really want it to."

Childhood

Like any other child I liked playing with other children. My brother and I were very close, so it seemed natural for me to be included in his circle of friends. I went to a school especially for children with disabilities, and there I made friends with girls and boys my own age. My girlfriends and I would play with our dolls, pretending that they were real people living within a real family setting acting out real family situations. In a sense, like other little girls, I think we were preparing ourselves for what we supposed our lives might be like when we grew up. I had boyfriends, too. Like my girlfriends, some of the boys had disabilities and some were able-bodied. Somehow, even at so young an age, there were often romantic feelings between myself and these boys. Even back then, I was beginning to be aware of my sexuality. I had my first kiss on the lips from one boy when I was eight, and then got "married" at age ten to another boy who was in my class.

The teen years

When I reached my teens, however, everything seemed to change. Gone were the days of playing with dolls and the mock marriage ceremonies during recess. The age of innocence had seemingly disappeared overnight. The rules had suddenly, inexplicably changed. Everyone was becoming concerned about their body image, trying to fit in, trying to find their own place in the world. Like other teenagers, we began to find fault with the way we looked, becoming over-critical at the sight of the slightest flaw. The people on television, in movies and in the music industry really didn't help any either. They seemed to be so beautiful, so perfect, so flawless. Would we ever be like them? It seemed as if society and the media were saying that you had to look perfect in order to succeed in life. It didn't help that people with disabilities were rarely shown or mentioned in the media either, and if they were, they were portrayed as helpless and asexual.

I felt terribly confused and inadequate during my teenage years. My mother unwittingly added to these feelings by trying to give me

some advice. She told me to try not to become romantically interested in able-bodied boys. Her reasoning was that she thought that they would never want the responsibility of taking care of someone with cerebral palsy. It was her experience, she explained, that men liked to be taken care of, but they didn't particularly like to take care of someone else. I should stick to boys with cerebral palsy or other type of disabilities who would understand my needs, she told me. My mother wasn't trying to hurt me when she said this. She just wanted to save me from rejection.

Unfortunately, rejected I was — by both able-bodied boys and boys with disabilities! I found that a lot of boys with disabilities only wanted to become involved with able-bodied girls. They didn't want to stick to girls who happened to have disabilities. Indeed, they didn't think they should have to. One boy explained his feelings to me this way: "You live with your disability every day of your life. Why would you want someone who is exactly like you to remind you of your own limitations?"

There were some, admittedly, who didn't care whether a girl was able-bodied or not. Unfortunately, I just never "clicked" with these guys. Either they weren't my type or I wasn't theirs.

I learned that sometimes you can not help who you are attracted to. And so, despite my mother's warnings, there were times when I tried to catch the attention of able-bodied men. I was like any other woman. If I saw a good-looking guy I would want to sit and talk to him, maybe even flirt with him. A lot of these guys liked me, sure, but never in "that way". They said they just wanted to be friends.

It was unbelievably frustrating for me, and very demoralizing as well. I felt as if I were invisible, as if I were somehow a non-person. I felt as if society expected me to supress my sexuality and act as if it didn't matter, that it was just something that I would not, could not do. There were some people who assumed that I was void of any type of sexual feelings to begin with and needed to be protected from any kind of sexual intimacy. Outwardly I was the same person I had always been — cheerful, outgoing, optimistic. Inside I began to feel angry and resentful of these kinds of attitudes, and of all the restrictions that were being put upon me. I just could not understand what had happened to my life. As a child I was included in all aspects of life. Now I was excluded from a big part of life that most people took for granted. As a child people assured me that my dreams of having a husband and family of my own would be easily attainable when I grew up. Now that I was actually a grown up, it seemed like someone had suddenly changed the rules on me. I was still a nice person, wasn't I? I was a good person with a lot to offer. Perhaps I wasn't one of those perfect beauties on television or in movies, but I had my own type of beauty, didn't I? Why couldn't anybody see this? Why couldn't anybody get past my disability?

Young adulthood

When I was twenty-three my parents put me into Participation House (a home for people with physical and mental disabilities) for "parent relief" while they went away on their yearly two week vacation in the Carribean. It was there that I began having a relationship with one of the male attendants. He pursued me, kissed me, told me I was beautiful and desirable. After I came home from Participation House we started dating for awhile. Finally, I thought, I had found a man who liked me "in that way", who knew I had the same feelings and desires as any other woman. Finally, I could have a romantic relationship with a man just like any other woman. I was in love with him, or thought I was at the time, but I never fooled myself into believing that he loved me. Even so, when he broke up with me to marry another disabled woman it hurt terribly. Later on, I realized that what hurt most was the fear that I would never find anyone else, that this man was probably my last chance at happiness.

Romance at last

At twenty-nine I was resigned that I would die an old maid, a virgin, forever without a mate. If that is how things were going to be, then so be it, I thought. I had tried my best. And then, one day, something happened that changed my life. A friend of mine talked me into purchasing a computer and a modem. My friend also showed me how to access a computer bulletin board system (BBS) and communicate with people. From then on, I spent up to three hours a day in on-line "chat rooms" with total strangers talking about just about anything and everything.

One day I logged onto a BBS and began chatting with a fellow named Rob. He seemed sweet and funny, and I liked him, as he liked me, almost instantly. We chatted for hours and soon found out that we had many things in common. Even so, I didn't feel comfortable enough at first to tell him that I had cerebral palsy. I was afraid of how he might react. I couldn't face another rejection! However, because he kept

asking me if he could meet me and because he told me he thought he was falling in love with me, I felt like I had to break my silence. Amazingly, Rob didn't care about my disability. He still thought I was a wonderful person, he said, and wanted to meet me.

All my family and friends thought I was insane to go meet someone I had only chatted with for a month over a BBS, but I didn't care. I knew Rob would be just as he had seemed in the chat rooms of the BBS. I was right, of course. When we met that day, it was as if we had known each other all of our lives. We started dating after that, and soon fell in love. Neither of us could have been happier. It was as if we had been made especially for each other.

We have been married now for two years and are trying to start a family of our own. In fact, I was pregnant this past spring, but, sadly, I had a miscarriage. My family thought I was crazy for even considering getting pregnant the first time. Now they really think I am crazy for trying once again. After my miscarriage, one of my relatives made a rather glib suggestion to me that Rob and I should go out and buy a puppy instead of trying to get pregnant again. My family doesn't mean to hurt me. They are just concerned about my welfare. They think because of my age (I am thirty-nine now) and my disability, that I am too frail and fragile to give birth. I don't share their views and neither does Rob. Neither, in fact, does my obstetrician. The obstetrician I went to when I was pregnant has had several patients with cerebral palsy under his care who have successfully given birth. He thinks it's perfectly fine for me to do the same thing.

I want to have a baby with Rob, a small being that we can love, care for and raise together. But to just say that I want a baby does not nearly cover how I feel. It is not like wanting a pizza, a car or a new dress, nothing so mundane as this. It is a deeper feeling than that, more like a physical yearning, a terrible longing inside of me. The female members of my family must have experienced similar feelings when they decided to have children of their own. Why then can't they understand that it's the same for me?

It has always been like this: one set of rules for me, one set of rules for everyone else. It is so frustrating, and it gives me a terrible headache to think about it! I am not giving up, though. Rob and I will have a beautiful healthy baby one day, of this I am sure. And, I'm even sure my family will come around to accepting our decision and understand that we know what we are doing. They do love me after all. This is just one more of life's little hurdles that I have to get over. I mean, if finding Rob has taught me one thing, it is that if you want something badly enough you should never give up or be afraid to take chances.

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Mr. Right

ERICA SIMPSON

Erica Simpson is currently working out of her home. She is a talented individual who enjoys classical music. Erica doesn't have much time to pursue her writing so we are fortunate that she agreed to share some private thoughts in this issue of ***Communicating Together****.*

This topic is very private and personal. What I'm about to share could upset a few people who know me personally while others might empathize with me. Some might say I was wrong in doing what I did while others might say they would do what I did if they were in the same position. Whatever your reactions are doesn't change the fact that these things have happened.

Many of my friends have been able-bodied. In many ways, I'm told that I don't think like a "disabled person." I think and act like an "able-bodied" person although I was born with cerebral palsy. I use a wheelchair and use various AAC devices to communicate as well as my own speech.

I grew up with all the "normal" feelings, thoughts, and desires. It never occurred to me that I might not find "Mr. Right" one day. I still haven't given up totally but my expectations are starting to be more realistic. My "Mr. Right" had always been able-bodied and very capable of taking care of me with my disability. He was able to love me for who I was. Today, I'm a little more open to the fact that "Mr. Right" might be disabled and he might not be able to take care of me 100%. All I know is my "Mr. Right" will be my best friend and will be supportive of me as I will of him. We will love each other, hopefully till "death us do part." Whether "Mr. Right" will be able-bodied or disabled is an unknown and whether I will ever have the title of "wife" applied to me is unknown but I'm certain of this, I have been fortunate in having some "learning experiences" along the way.

How are you suppose to "neck" when your mother is sitting next to you?

I had "boyfriends" when I was a pre-teen and a young teenager. These guys were in the same class as I was. In spite of the fact that we were all in wheelchairs, we found ways to kiss. We held hands and experienced all the things that "puppy love" has to offer. Things didn't progress further than "puppy love" primarily because we each went our own ways. Also, it was very difficult at that time because local accessible transportation was unheard of. The feasibility of dating was a joke. If we did get to go out on a "date", one of our parents would have to come along to provide the transportation and assistance. How are you suppose to "neck" when your mother is sitting next to you?

My first real experience with what I thought was love happened in my late teens, when I was 18 and living away from home. I was in an independent living facility where attendant care was provided. The janitor and his wife befriended me. They would have me over to their place quite often. Slowly, the janitor and I developed an attraction to each other. Obviously, I didn't have the intention of carrying out the fantasies I had for him. He was a married man. I certainly didn't want a married man. Everything I believed in was against married people being unfaithful to their partners. Unfortunately, to my dismay, this didn't stop my feelings and my responses to his "come-ons."

First, it was heavy necking and fondling. That felt physically gratifying. He was doing things to me that I physically couldn't do to myself. Unfortunately, it didn't stop. Eventually, we went "all the way" and had intercourse. Precautions were taken so I wouldn't conceive. It was very consensual. I don't want people thinking I was raped because I was *not*. We kept this up for some time. My physical desires were being met and I felt loved. I felt special and I was told that I was a very capable and satisfying partner. What more could I want? For the first time in my life, my disability wasn't an obstacle. Since he was able-bodied, he could do everything: undress me, put me on the bed, then dress me afterwards.

About a year and a half after the relationship started, it finished. He never returned — no explanation. He just walked right out of my life. I saw him a few years later and he said he wanted to come over and offer an explanation. Years later I have given up on waiting to hear from him.

This indeed was an extremely hard lesson for me. I learned a few

facts about myself, though. I was comfortable with who I was. I knew I could have a relationship with a man, that was both emotionally and physically intimate. I knew there were men out there who could look beyond my physical disability and see the person inside my body.

Shortly after this relationship, I met somebody else. We had an actual dating relationship. We would go out. He was able-bodied so he could transfer me in/out of the car. Our relationship didn't go anywhere but I don't think it was due to my disability. It was due to the two of us being too different.

Some years later I got myself into another situation with another married man. Once again, I didn't initiate the romance. We attended a lot of the same functions. This individual provided transportation for me and sometimes would feed me while we were out. He was very accepting of my disability and was comfortable with me. Things started happening. Part of me wanted to run but the other part was longing for an intimate relationship again. I missed the touch, the closeness, and the emotional support of having a "special someone". This relationship was more emotional then any other relationship I had had before. I could share things with him and know that they were safe. Likewise, he could share things with me. Yes there was the aspect of an intimate relationship. He was able-bodied so he could do whatever I needed in order to be intimate with him.

This relationship lasted six years. but very few people knew about it. I was the one who broke it off since it was not going anywhere. He assured me that I would make someone a wonderful wife someday since I was able to give everything needed to be a good wife. I understood him emotionally and was able to be supportive and encouraging besides providing the physical intimacy. Unfortunately, circumstances in his life weren't right for providing me with what I really wanted — a husband.

As I look back on these experiences, I realize that my speech impairment hasn't been a barrier to a relationship *once the person has gotten to know me.* Yes, my speech impairment and physical disability may hinder men from approaching me at first but people who get close to me can understand me. As well, I feel there's an unspoken language between two people who share love and intimacy. I still long to find "Mr. Right". But I'm also content in knowing I have experienced intimate relationships — regardless if they were right or wrong.

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AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

The Official Journal of the
International Society for Augmentative and Alternative Communication

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Sexuality and Communication

RICK ENRIGHT

Rick Enright

Rick Enright is an enthusiastic and empathetic individual who is currently working as a social worker at the Thames Valley Children's Centre in London, Ontario. Rick has been involved in research in the area of sexuality and disability and also has several clinical experiences which he brings to the subject. He has written a book geared to informing adolescents about sexuality. The intent of the book is to open up the lines of communication on this taboo subject. It is an excellent icebreaker, which as Rick explains, is an attempt to break the "conspiracy of silence".

It is one of the great universal truths that good communication is one of the essential pre-requisites for all relationships. Friendship, companionship, workplace interactions, and even casual neighbourliness all depend for much of their vitality on simple communication. The word simple is emphasized here because if you are old enough to be reading this article, you are almost certainly aware that communication is seldom simple. Often it is very challenging. It is not necessary to look very hard to see examples of the consequences of poor communication. The root of most disagreement, discord, misunderstanding, rudeness or conflict is poor communication or the absence of communication. Wars have been fought and countless human beings have died or suffered over disputes that began as a simple failure to understand a different point of view.

The root of most disagreement, discord, misunderstanding, rudeness or conflict is poor communication or the absence of communication.

Ask anyone who is in a permanent, long-term, intimate relationship what is the most important factor in keeping that relationship alive and dynamic. Most of the time, the answer you will get is *communication*. When that relationship includes a sexual component, the same fact applies. The foundation of healthy sexuality, like the foundation of all healthy relationships, is communication. How then does a communicative impairment affect sexual expression and problem solving?

Sexuality of physical disability

The professional experience I bring to this subject is primarily with adolescents and young adults with chronic physical disabilities. Cerebral palsy, spina bifida, acquired brain injuries and muscular dystrophy are the most prevalent diagnoses. So it is necessary to first put this topic in the context of physical disabilities in general before we look at communication in particular. In the last several years, I and a team of colleagues from several professional disciplines have been involved in a research project to explore the level of sexuality information, awareness and experience among young people with physical disabilities. While it is not possible to generalize to all people with disabilities, here are some of the things we discovered in the population we surveyed:

1) *Severely limited opportunities to acquire information related to sexuality and relationships.* When such information is available it is most likely to come from parents or professionals. Exposure to information from media or peers is very limited. Moreover, our experience has shown that any discussions relating to the topic of sexuality generally need to be initiated by a concerned professional. Many families of young people with physical disabilities seem to have difficulty knowing how or when to initiate this discussion. This seems to result in a tendency for those with permanent disabilities to be seen by others, and ultimately to perceive themselves, as asexual beings, or incapable of having sexual relationships.

2) *A low level of general knowledge of body awareness, sexual knowledge and sexual response.* Many young people with physical disabilities have been excluded from school-based sex education programs, or have attended such classes as passive observers rather than active learners. Questions about the impact of physical disability on

sexuality are seldom asked, and even more rarely answered. This reflects a great deal of anxiety and uncertainty on behalf of both the student and the teacher of sex education. Teachers are as afraid of being asked questions for which they do not have answers as students are of asking them. The result is a mutual conspiracy of silence which prevents embarrassment on both sides, but results in a profound information vacuum. Students with disabilities are therefore not well informed about anatomy, physiology and normal sexual response. They are even less well informed about the global consequences of their disability for their own bodies, and how it affects their sexual response.

To compound this problem, there is a serious shortage of accessible and appropriate information about sexuality for those with physical disabilities. In an attempt to resolve some of this problem, I have written a book, released in 1995, entitled "*Caution: Do Not Open Until Puberty! An Introduction to Sexuality for Young Adults with Disabilities*" (see reference below).

3) *Significantly diminished and delayed sexual experience.* While many parents of adolescents would probably be relieved to know that their offspring were not engaging in precocious sexual activity, the fact remains that adolescence is the normal time for the onset of sexual awareness, self-exploration and experimentation with sexual relationships. It is therefore of some concern that the great majority of adolescents with physical disabilities have little or no experience with either personal or interpersonal sexual activity. The overwhelming majority of those we surveyed had never masturbated, experienced orgasm, or had any mutual sexual experience with a partner. These factors can be traced directly to the more obvious consequences of severe physical disability — decreased mobility, increased dependence on adults, lack of privacy and limited opportunities for socialization. If you are usually with an adult caregiver, seldom alone and have few independent interactions with peers, any kind of sexual activity becomes virtually impossible.

It is worth mentioning here that many of the adults I know with disabilities do not begin to confront these issues until they are well into their twenties. Even this is dependent upon them living in an environment which affords them enough autonomy and privacy to do so.

These are some of the more disturbing findings of the survey done with young adults with disabilities, all of whom were of average intelligence and all of whom were independent, competent, verbal communicators. None of the participants of this survey had significant communicative impairments. None used any form of augmentative communication. None required a communication intervenor. Yet their collective sexual experiences could fairly be described as impoverished.

Sexuality and Communication Impairment

The natural question to be asked here is: "How does a communicative impairment affect sexual learning, sexual expression and sexual experience?" While I can't answer that question from a research perspective, clinical experience does offer some insight. The same principles observed in those with physical impairments apply to those with communicative disabilities. In fact, any condition which reduces independence, privacy, self-awareness and social interaction will likely have negative consequences for the development and expression of sexual knowledge, sexual experimentation and mutual sexual relationships.

At the risk of asserting the obvious, the more complex the disability, the more likely it is to have serious implications for interpersonal relationships, including sexual relationships. I know this to be true because I know a number of young adults with serious physical and communication disabilities. Most of them are not currently involved in a stable, long-term sexual relationship, nor have they ever had one. Many of them have never had any kind of sexual relationship at all, long term or otherwise. Those young adults I know who have had intimate relationships tend to be either very good communicators or female. This may reflect the still prevalent assumption that it is the responsibility of the male to initiate relationships. When it comes to socializing and dating, males with communication impairments have two strikes against them before they begin.

I had a striking example of this dilemma in a group I run for adolescents with disabilities. One young

Safeguarding Individuals with Severe Communication Disorders

Trainer: Barbara Collier

Children and youth with physical disabilities combined with severe speech disorders are 2-6 times more likely to suffer physical, mental and sexual abuse. Victims who cannot communicate cannot prevent or report assault or abuse, cannot access the justice system, and are unable to receive the counseling they need (Farrar & Brewin'96).

Participants will:

- increase their awareness of the risks of abuse for individuals who have severe communication disorders and strategies to assist clients in providing them with the words and skills they need to communicate.
- learn practical strategies for developing safe guards for people who use augmentative and alternative communication (AAC) systems.
- learn techniques to communicate with users of AAC and how to use these techniques to assist with disclosure, reporting and obtaining assistance.

Level: Intermediate

Number of Participants: 30 -35

Who should attend: All people who work with children and youth with communication disorders and those involved in the investigation and legal process.

Dates	City	Location
May 4	Toronto	Best Western Primrose Hotel
May 11	Kitchener	Four Points Hotel
May 21	Belleville	Best Western
May 25	Sudbury	Howard Johnson

Workshops start promptly at 9:30 a.m. and end at 4:00 p.m. Light refreshments will be provided at breaks, however lunch is the responsibility of the participant. Restaurants will be easily accessible.

About the Trainer

Barbara Collier is a Speech Language Pathologist with 20 years experience working with adults and children with severe speech disorders. She was a senior consultant with The Augmentative Communication Service, Bloorview MacMillan Centre; Director of The Adult Adaptive Communication Service and Senior Consultant in Service Development and Training (AAC) with The Ministry of Health's Assistive Devices Program.

She has provided training in AAC to over 800 Speech Language Pathologists and Occupational Therapists in Ontario and has implemented training programs to emerging AAC clinics at a number of hospitals. She has published many articles, received a number of awards for her work and is an invited speaker at national and international conferences. Barbara is currently a private consultant providing client communication services and agency training programs.

Don't miss out — register today!

Workshop name _____

City _____ **Date(s) of Workshop** _____

1. Name: _____

Position: ❑ Child and Youth Worker ❑ Developmental Worker ❑ Social Worker ❑ Psychologist ❑ Foster Parent ❑ Community Worker ❑ Supervisor ❑ Administrator Other
(specify) _____
Indicate program type: ❑ residential ❑ community

2. Name: _____

Position: ❑ Child and Youth Worker ❑ Developmental Worker ❑ Social Worker ❑ Psychologist ❑ Foster Parent ❑ Community Worker ❑ Supervisor ❑ Administrator Other
(specify) _____
Indicate program type: ❑ residential ❑ community

Agency: _____

Address: _____

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Telephone: (_____) _____ **Fax:** (_____) _____

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My agency is a member of: (check one)
❑ Ontario Association of Children's Mental Health Centres
❑ Ontario Association of Children's and Youth Institutions (ONTCHILD)
❑ Ontario Association of Community Living
❑ Ontario Association of Residences Treating Youth
❑ Association of Native Child & Family Services

Cost: Member Agencies: There is NO fee for members of the above associations
Non-Members: One day workshop: $125.00 Two day workshop: $200.00
Please enclose cheques payable to: Safeguards: Children's Services Training

New cancellation policy:

Member: If a registrant cannot attend a workshop, they must notify Safeguards office at least 3 working days prior to the workshop. People canceling after that and/or not attending a workshop will be charged a cancellation fee of $50.00. Substitutions may be made, however registrants must notify Safeguards as early as possible.

Non-Members: Cancellations received up to 3 working days prior to the workshop are refundable, minus a $50 registration service charge. Registrants who do not cancel and/or do not attend are responsible for the full fee. Substitutions may be made, however registrants must notify Safeguards as early as possible.

Mail/Fax forms to: Safeguards: Children's Services Training
9005 Leslie St. , Suite 108, Richmond Hill, ON L4B 1G7
Tel: (905) 889-5030 Fax: (905) 889- 7155

REGISTRATION WILL BE CONFIRMED WITHIN TWO WEEKS

man in the group with quadriplegic cerebral palsy and moderately impaired speech had avoided any discussion of sexuality during the entire three years he was in the group. One day however he nervously asked the critical question that had been unspoken for all that time: "Am I going to have to pay someone to have sex?"

Is there a simple prescription to resolve this dilemma? With severe disabilities, there are seldom simple solutions. But for caregivers or professionals working with young people with significant communication impairments there are certainly strategies to try to reduce these effects.

1) *Give frequent opportunities to make choices.* Start early with this principle and do it consistently. With older children and adolescents don't just encourage decision-making. Insist on it! Dependency is an insidious process which starts from good intentions and the necessity of helping a young child who cannot safely be independent. If the pattern continues for too long however, it results in a young adult who is unable or unwilling to make independent decisions. Clearly there are risks involved in some choices as life is literally impossible without risk. If that is the case, then warn them of the possible consequences but let them choose anyway. In this way, the eventual decision to enter a sexual relationship is just a choice like countless other choices. The inherent risks of emotional vulnerability, unwanted pregnancies, sexually transmitted diseases and AIDS can then be seen in the context of all the other risks that every independent person weighs every day of their life.

2) *Adolescents need frequent opportunities to be left alone- either with their peers or by themselves.*
This doesn't mean giving them free and unsupervised access to sex, drugs and rock'n'roll! It does mean recognizing the fact that sooner or later they will have to survive without you. You both need to practise letting go and going out into the world. For those who have needs for physical assistance, maybe friends can begin to take over those tasks, enabling adults to stay home where they belong. At the very least, adolescents with disabilities are entitled to private space and closed doors when that is what they choose.

3) *Don't deal with tough issues by avoiding them.*
Human beings sometimes tend to encourage only those questions they feel competent to answer. With sexuality, this results in what I call 'the elusive expert syndrome'. Most of us know that we should be providing information, but many of us also feel we shouldn't give advice without some level of personal experience or specific knowledge. Since most adult caregivers have no personal solutions to the problems posed by disability, we tend to want to refer the issue to someone who is better qualified. This may seem to make sense, but in ten years working with clients with physical disabilities, I have yet to find an accessible expert on the issue of sexuality and disability. If I have a client in my office who needs help, and the only 'local' expert in the field lives four time zones away, referral is not a solution.

4) *Treat questions about sexuality and disability as you would any other problem which needs a creative solution*

a. Acknowledge your lack of expertise, but assert your willingness to help.
b. Ask all the questions you can think of together.
c. Gather as much information as you can find.
d. Consider the options and discuss the possible outcomes of different solutions.
e. Weigh the option(s) with the best chance of working for this person in this situation.
f. Let the individual make the choice that works best for him or her.

This will not always result in the ideal solution. Sometimes the answers will be quite unsatisfactory. But one of the other great truths of humanity is that we are imperfect creatures, and often our solutions are imperfect as well. If we wait around to find the perfect answers, we could wait for a long time. Meanwhile we might miss out on a lot of living.

Oh, and by the way, remember that young man in group with the tough question? He found his answer. He is engaged to be married.

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(See page 6 for reference)

Intimacy

TIM KINNEY

Tim Kinney has worked for eight years with Ontario Federation for Cerebral Palsy and is responsible for programs related to adults. Tim co-ordinates the Federation's involvement as a co-founder of Accreditation Ontario along with Ontario Association for Community Living. Accreditation Ontario is dedicated to improving the quality of life for individuals who have a disabilty. Services include training, consultation and an accreditation program, Personal Outcome Measures, 1997. This article was adapted by Tim Kinney from material produced by The Council on Quality and Leadership in Services for People with Disabilities.

In reviewing articles and books I found some information about sexuality but very little about the quality of relationships that most people yearn for. I have found material produced by *The Council on Quality and Leadership in Services for People with Disabilities* (The Council) to be very insightful about intimacy.

The Council's newly released publication *Personal Outcomes Measures (1997)* provides a comprehensive approach to understanding and measuring quality of life as defined by the person with a disability. Intimate relationships are one of twenty-five categories that individuals have identified as crucial to their quality of life. What has emerged from hundreds of interviews is that sexuality tends to be one aspect within the broader social context of *intimate relationships*.

What is intimacy?

Intimacy is sharing something with another person that you would not share with other close friends. Each intimate relationship has some combination of social, emotional, physical, intellectual, and spiritual aspects. Each relationship is unique.

Intimacy is present when people care and feel deeply about each other. Intimate relationships mean that people are committed to one another, trust each other and know that they will not be rejected by the other person. The degree of commitment and trust will vary from one relationship to another. Often intimate relationships will include physical affection.

With close friends or a family member this might include expressions such as hugging, sitting close to one another, or holding hands. For some people physical affection can also include sexual contact.

How is intimacy different than sex?

Intimacy should not be confused with casual sexual relationships even though in today's society the term "intimate" is often used to mean any experience of sexual contact. Sexual contact without the presence of some of the other aspects of intimacy, for example without deep feelings, commitment or trust, is not intimacy.

Can't get no satisfaction?

Everyone old enough to read this already knows that together with the wonderful potential for satisfaction, intimate relationships can sometimes be a source of deep hurt and confusion. What is most important for us to understand is that each person defines the meaning of intimacy in his or her life. Each of us can learn from our experience with other people. But it is important to know that we do not have to be just like those other people, or to have the same types of intimate relationships that they have. It is important that each of us try to discover what types of intimacy and relationships are most satisfying for us.

How will I know when I am getting enough, intimacy that is?

Intimate relationships are important for most people. However there are times in the lives of many people when they do not have an intimate relationship or the one(s) they have are not satisfactory compared to their needs. This experience varies from one person to another. And it is also important to know that no one is required to have intimate relationships.

For some people, relationships with family and close friends may meet most or all of their needs for intimacy. Many people also have needs for intimacy that also include wanting and hopefully having a sexual relationship.

Here are some sample questions that might help you to identify the kinds of intimate relationships you have in your life. Please feel free to change the questions around so that they suit you. Remember there are no correct answers.

- Is there someone with whom you share your personal thoughts or feelings?

- Whom do you trust to talk with about private concerns and feelings?
- Who is there for you when you need to talk?
- With whom do you share your good and bad feelings? Is this enough for you?

Support for intimacy

A person with a disability, whatever his or her needs for support services, should have the choice and opportunity to develop close personal relationships. Their options should match what is available to people without disabilities. Services should not prohibit or present barriers to the development of close personal relationships. Personal desires for intimacy with others must be respected and supported. *Respect for the whole person is the foundation of support.*

Yet disrespect for people is a huge problem and often involves some of the staff of agencies whose reason for existence is to support people. This is also a problem within many families and the community as a whole. Compared to someone who does not require support from others, individuals who do require such support will, by necessity, have less privacy with respect to information about themselves. How staff and significant others handle this knowledge is incredibly important. Unfortunately, what many individuals appear to be learning from their relationships with staff and others is that it is not safe to let other people know you intimately. Sometimes individuals are not aware of the gossip about them, but some staff make a point of letting the person know that they know. For example, staff may tell the individual whether the person did or did not come home last night, or whether they had a visitor. This big brother mentality is very harmful, particularly to individuals who are just beginning to learn about relationships and trust. Respect also involves the way people are addressed and whether their opinions and preferences are valued in day to day interactions.

Supports instead of restrictions

No one should be prevented from pursuing intimate relationships. If there is a specific concern for the safety or exploitation of the person, supports should be provided to enable the person to safely explore his or her needs for intimacy. The role of people who support individuals is to assist the person in accessing information and to provide appropriate experiences for the person to practise making choices. Support people should also arrange access to opportunities for enhancing relationships. Support means providing assistance for people to learn about relationships, find and use transportation, and make decisions.

One of the most common and important forms of support that makes a difference for a person is actually non support or *non-interference*. Essentially this means to take steps to try and ensure that the support we provide is not interfering with a person's life and relationships. Support providers must meet with individuals from time to time to check to see if there are ways in which we or our services are getting in the way of the person.

A common area of 'interference' that undermines a person's efforts to form and maintain intimate relationships is the way that friends and family are treated by the agency. Common barriers include failing to respect privacy in subtle ways, refusing to accommodate individual needs related to having guests over, inflexible timing or availability of supports, and restrictive policies. Individualized assistance is essential if people are going to develop and maintain relationships. For many people this might be as simple as non-interference. Others will require some form of support. Agencies and families have to get over the misconception that asking people if they need some support is 'an invasion of privacy'. The adage that "if you do not ask you will not know", holds a lot of merit in working with people. Or as Mother Theresa said "*you have to get close to people, you cannot help them from a distance*".

Conclusions

In conclusion, people define their own requirements for personal relationships and types of intimacy. The choices people make should be respected by all who support the person. People have the right to develop and express their sexuality. Each person is responsible for his or her relationships and sexuality. No person can dominate or exploit another.

The obligations of the support people are to assist the people they are supporting to explore their own feelings and desires, to evaluate their experiences, and to make choices about forming, pursuing, and maintaining intimate relationships with others. People who lack experience with, or knowledge about, intimate relationships and sexuality, should be presented with options for training and support.

***Note**: The opinions expressed here are those of the author. They do not necessarily represent those of the Ontario Federation for Cerebral Palsy or The Council on Quality and Leadership in Services for People with Disabilities.*

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What is so Bad about Being a Sex Expert?

CORY SILVERBERG

*Cory Silverberg is a worker-owner at **Come As You Are**, a co-operatively run, accessible sex store in Toronto, Canada. For the past ten years Cory has worked in the retail sex industry as a buyer, consultant, and trainer. He has presented on the topic of sex toys, sexual communication, and sexuality and disability at workshops and conferences both in Canada and the U.S. He can be reached at 416-504-7934, or email:*
csilverb@interlog.com.

As a kid I always wanted to be an expert. Growing up the youngest of three children in a family full of therapists, I thought it would be the best thing in the world. After all, people would admire me, they would pay close attention to everything I said, they would pay me lots of money and all I'd have to do was speak my all-knowing mind. Heavens! Over time, I lost this ambition and moved on to other things. In the past couple of years the word expert has begun to be used to describe me, and I realize that my views have changed considerably.

Firstly, somewhere at university I discovered that unless you are John Gray or Dr. Ruth you aren't likely to get rich from being an expert (and I'm not really sure about Dr. Ruth). Second, I discovered that being an expert in Western culture usually has less to do with knowledge or wisdom than it does with sounding smart, looking good, and saying the right things at the right time. We're taught to trust experts, to seek out their advice and put the paths of our lives in their hands. This is particularly true when it comes to sexuality. With alarming regularity, people come forward as experts on sexuality, they tell us how to have sex, how not to have sex, when, where, and with whom we should be having sex. If you listened to everyone's advice, you'd go crazy. Yet we listen. So few of us are raised to think of ourselves as sexual, to think about sex at all, that most of us are afraid to communicate about it. We are afraid to come out as sexual beings (and worse still, sexually naive beings). This fear, which is heavily influenced by the media makes us cling to anyone willing to do it for us. I have had the strange experience of being on the expert end of this frustrating relationship a number of times in the past few years. A little background is in order.

I was raised by two sex therapists in a very liberal, sexually progressive, household in the 1970's. When I was seventeen I got my first job in a sex-toy store and I have continued to work in sex toy stores to this day, while getting an undergraduate and graduate degree in psychology. Seven or eight years ago, I was fortunate enough to meet and become friends with some folks who were disability activists. Encouraged by their work, and learning about the dearth of resources in the area of sexuality and disability, I started researching.

As a sex store worker it is my job to help people access information and products that allow them to explore their sexual selves. This was no different. It's interesting that this work got little attention from others. No one seemed interested in some guy who worked at a sex-toy store. It wasn't until I completed a thesis in an academic setting that I started getting attention.

For my undergraduate degree in psychology, I wrote a thesis on sexuality and disability. And even though I have never lived with a major disability, and at the time I was only twenty years old, I almost immediately started getting calls from people ready to name me an expert simply because I expressed interest and comfort with the topic. The first was a reporter for a university newspaper who heard I was writing a thesis on the topic. She wanted quotes for an article she had already written. Next I was asked to speak at a conference, then a workshop, and on it went.

I find it fascinating and frustrating that I am often asked to speak or do an interview on the topic of sexuality and disability while friends and colleagues who live with disabilities struggle to get media recognition for their projects, books, magazines. This is particularly aggravating in an environment that should be consumer driven. It's not

that I doubt my abilities as an educator, or my ability to make meaningful connections with people that cross traditional disability barriers. I do my job very well, and have made many friends along the way. Nonetheless, in the context of the consumer movement, it's my belief that the more consumers do for themselves the better. I can be cognizant of my privilege, and work towards eliminating the barriers it creates for me, but I cannot erase it. It is part of who I am. Now try explaining this to a TV journalist who wants a thirty second soundbite about how people with disabilities have sex. They aren't interested and don't have the time to listen to the issues. They just want the expert opinion.

The most insulting thing about being called an expert is that I suspect in this case it's for all the wrong reasons. Mainstream culture wants experts like me not because I know what I'm talking about and I do my job well, but because I'm accessible. My first clue to this was during an interview about the store I work at. Half way through the interview I was holding a vibrator and told the reporter that it was one of my favourite toys. I didn't go into detail, but I immediately sensed the reporter's discomfort with my forthright comments. The attitude I got was:

> "It's okay to talk about being open sexually. It's okay to support people's right to choose how they define themselves sexually. But, for pete's sake, don't tell me about your own sexuality."

This really took me aback. I thought we were having a great interview, that this reporter was really sex-positive and open to what our store was trying to do, and then wham.

The reporter became uncomfortable because I was now talking about my own pleasure. Worse still, I seemed to enjoy talking about it. One reason that I am a perfect disability and sexuality expert is that since I have no visible disability, they assume I am removed from my subject matter. There's less of a chance of me saying something personal which is potentially embarrassing. This ignorance on the part of media helps no one and can reinforce a variety of stereotypes.

First, people assume that if I don't look like I have a disability, then I don't have one. In doing this, they re-enforce all the stereotypes and barriers that make life difficult for folks with "invisible disabilities". I have never been asked by a reporter or any mainstream media whether or not I have a disability.

Second, people make the usual mistake of putting disability before all else. When they assume I'm distanced from my subject because I'm non-disabled, they make disability the lens through which everything is seen.

So few of us are raised to think of ourselves as sexual, to think about sex at all, that most of us are afraid to communicate about it.

When I give talks I always tell people ahead of time that I talk about sexuality. I know about disability, I use examples that involve disability; and my presentations are disability-positive. But primarily I'm talking about *sexuality*.

While folks who live with disabilities do have far more barriers to accessing information, education, and services related to sexuality, they do not have a diminished ability to be sexual. Most of the issues around sexuality apply equally regardless of disability. Being sexual is feeling good about ourselves, our bodies, being alone, being together, being in control, giving up control to someone we trust and maybe love, being able to share our desires, and being able to meet them ourselves. The ways we go about this are infinite, but the desire for pleasure, however you define it, is about the closest thing to a universal I've come across. When I talk about sexuality these are the things I refer to. And they are as relevant to me as they are to someone who may not communicate the same way I do, or get around the same way I do. And when the media miss that point by placing me outside of sexuality, as the expert, they lose so much of what can be transformative in communicating about sexuality.

Now don't get me wrong. I love my job, and wouldn't change it for anything. I get paid to talk and learn about sex all day. Working with people who don't easily fit into mainstream constructions of sexuality has helped me be more comfortable with my own non-conformities. The thing is I'm no expert on "sexuality and disability." The only thing I'm really an expert on sexually is myself. And that's an expertise that comes not just from lots of studying and having letters after my name. It is from years and years of diligent practice. What we need is more personal experts, and experts with experience living with disabilities who are willing to come forward and share that kind of expertise with the rest of us.

§

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Sexual Feelings are Alive and Well in Chronic Care Hospitals Too

ALDA STEPRANS

Alda Steprans

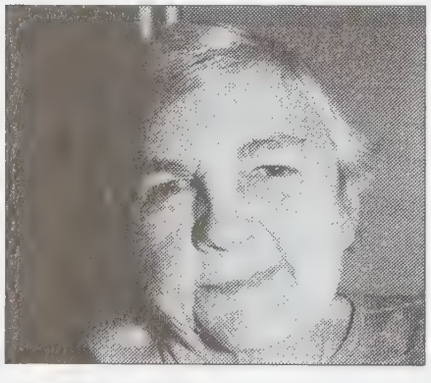
Sexuality, in the various forms sexuality takes, does not simply disappear because a person becomes very seriously ill and has to move to an institution. The residents of the chronic care hospital where I work have unique sexual needs. Indeed the issues become more complicated as physical changes occur in the body, due to chronic illnesses, and as social conventions in an institution impose certain limitations on people.

Just as sexuality is expressed in a myriad of ways by the residents of this institution, it is accepted or experienced differently by the many staff members. One of the largest hurdles to overcome in an institution is privacy, both physically and socially. In a chronic care hospital, where residents are dependent on staff for so many needs, staff do come to know their patients, in a sense intimately (of course, not in the sexual connotation of this term). The views and needs of any one resident or staff member may easily affect the views and needs of other residents and staff members. It sometimes takes very creative thinking, and a great deal of excellent communication, to find appropriate ways of respecting everyone's needs.

I certainly won't pretend to be an expert in the area of sexuality in institutions and hope that an article on this topic will be written by someone more knowledgable for some future issue of ***Communicating Together****. The subject of sexuality in institutions has not been altogether neglected in the literature. It has received attention wherever there have been sensitive caregivers, aware of those in their care as being not only physical entities, but also as complex social and psychological beings.*

I'll Get By

AUDREY McGEE
Assisted by ALDA STEPRANS



Audrey McGee

Audrey McGee is 75 years old. Several years ago she suffered a stroke. She states that since then, "the worst thing about the stroke is not being able to talk or spell". That may be so but Audrey can certainly communicate about the things she cares about.

My husband's name was George. This year we would have celebrated our 50th wedding anniversary. George died in 1993, after we had been married for 45 years. For our 40th wedding anniversary George gave me this necklace. It has a pendant that spells the word LOVE. I still wear it all the time.

We were very happy. George was a firefighter. He worked long shifts and the job was dangerous, but we were well-off financially. Our mortgage was paid off and there were no financial worries. We both liked to travel. Our favourite place was Florida, but we travelled a lot in Canada too — to places such as Prince Edward Island and Nova Scotia — in a recreational vehicle. We also went to Vancouver, Alberta and Saskatchewan, but for that trip we went by plane. On my 70th birthday we went to Atlantic City and Cape May. We had a fantastic time. We gambled. We didnt win any money but it was fun! In January, 1993 we went on a cruise to the Cayman Islands and stopped at Hell (a little town on one of the Islands). Hell wasn't very big, but it had a post office and a few stores.

We loved each other very much and were good friends. That didn't mean we did not argue every now and then. I miss George very much and am very lonely without him. He died suddenly, of a heart attack, on December 10th. Just the day before he died he had taken me Christmas shopping. Christmas time is still very hard for me.

We liked to go dancing. Our song was *I'll Get By*, by the Ink Spots. That was playing when we got engaged on October 24, 1944 at the Old Mill

Restaurant in Toronto. Our daughter Vickie was also born on October 24, but in 1952. Sometimes, when I was cooking, George would grab me and dance with me. We used to go down to the Palais Royale by the Lake Shore in Toronto, or to Sunnyside Pavilion, where it was very romantic to dance outside under the stars and the moon. The last time we danced was a week before George died. George asked the band to play our song, but they didn't know it. We were very disappointed. We loved to dance!

On our 25th wedding anniversary we made new vows of marriage in our church. We had a big party and invited all our friends. For our 50th wedding anniversary we were going to get remarried again and go to France. That was our dream. I'm sorry I'm crying, but it's painful to remember so many nice things. I miss him.

George did everything he could to help me. He helped a lot of people. He was good to my aunt and uncle. After they came home from the hospital after being sick, they stayed with us. They were 95 years old. My uncle died and then my aunt went to live with my cousin, Maria. I would be very happy if George could look after me now. I know he would.

My advice to all people in their lives together is that you have to care about each other and about other people around you as well.

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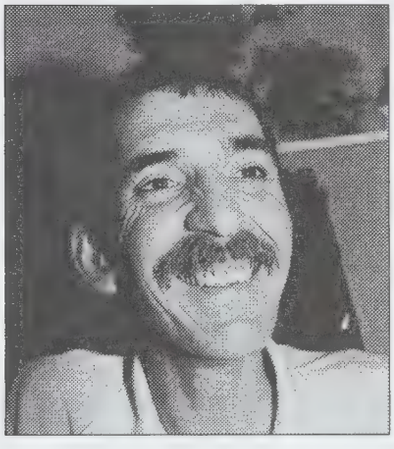
Reach Out and Touch

STEVEN HANLON
assisted by ALDA STEPRANS



Steven Hanlon

Steven is a regular contributor to ***Communicating Together****. Steven has Huntington's disease which has severely limited his physical mobility. But it has certainly not limited his spirit.*

I still love to hug my wife, Kim. She is very special to me. Hugging has always been important to me. That is enough for me now. It feels good just to be physically close to somebody. Kim comes in to see me once a week, sometimes more often. She works full time and goes to school. She is very busy. She's a good lady and very pretty. I missed Kim a lot when I first came to the hospital. Now I am busier and know more people and don't feel so lonely. It is hard living in a hospital where Kim and I can't be physically closer. Kim hugs me a lot when she comes to visit.

I miss hugs and being touched in a special way. I don't feel a hug is sexual when other people hug me, only when Kim does. But, it is still nice to be touched and hugged by other people. Touching lets me know that other people care about me as a person. Kim's hugs have a special meaning. They hold special memories for me. I liked the hospital's *Hug Week*, when staff and visitors could hug me. (*Hug Week is the week before Valentine's Day, when residents collect the signatures of those family members, hospital visitors and staff, who have given them a hug. Its a good excuse for hugging in an environment where people have to keep a professional distance.*)

I have some lady friends in the hospital. We are good friends. I try to reach out and touch my friends. It is important. I do sometimes feel sexually frustrated. I can't physically do anything any more. I am a person and its hard to control those feelings.

What about love? I think you need to love someone to have sex with them, but you don't need to have sex in order to love someone. I love Kim. What is most important however is knowing that Kim loves me.

I have a lot of friends. I don't love them, but I feel very fond of them. I have a lot of friends in the hospital I live in, especially other residents and some of the staff. I know many of the staff care about me in a special way. They talk to me as to a friend. They share some of their personal experiences with me and make me feel that I am a special person in their lives. I like being teased. It lightens my heart. I like funny people — time goes by faster when I laugh.

§

Coming Out

GEB VERBURG

Geb Verburg

I have written about many things in this column and more than once my knowledge of what I wrote about was not first hand. I have always had the benefit of great advice, although all shortcomings have been and are mine entirely. For this column I feel a bit more out of my depth than usual because I do not personally know a person with a disability who has "come out". I suggested this topic at our annual editors' meeting because the odds are that there are people with disabilities who are gay or lesbian and for them the issue of coming out of the closet is likely to be even more of a problem than for able-bodied lesbians or gays.

Coming Out = ...

Eric Marcus (1993) defines *Coming out of the closet* as being honest with those around you — friends, family, colleagues, and so forth — about your sexual orientation, about who you are. I believe that it would be very difficult for teenagers or young adults with disabilities to take that step and tell their parents and other people in their lives that their sexual preferences are different. Sexual expression for a disabled person is already complicated, and doubly so for those who have a different sexual orientation. The risk of rejection, the chance of alienating the people that they depend on, not only emotionally but for physical and survival needs, may be too great for these young people to dare to come out of the closet.

Acceptability

Even though we are living in relatively enlightened times, sex is still far from being an openly discussed and candidly treated subject. Homosexuality fares little better. By the early 1990s homosexuality had moved from being "unprintably scandalous to being acceptably scandalous". Sex of , with, and among persons with disabilities or of people that are considered marginal (ill, disabled, even old) is still either a taboo or something that has not had enough news coverage to make it into a printable or acceptable part of our lives. Having an unusual sexual orientation in combination with a marginal societal status is like having two strikes against you before you even start the game.

Obstacles

In my column in the previous **Communicating Together** that dealt with sexuality, I commented on how, for a person with a disability, the perfectly normal desire to engage in sexual acts becomes an obstacle course, not just because of the attitudes and misunderstandings of society, but because of the physical obstacles in their way. I did not just mean bodies and body parts that may not always be as cooperative as one would wish. I also meant wheelchairs that are not designed for amorous trysts, ventilators that tend to get in the way, attendants and attendant services which have their own moral convictions which may be helpful, but may also be prejudiced.

Disability Sex Stories and AASE

I would imagine that there is a small trove of stories told by people with disabilities about how they had to circumvent parental, clinician, and attendant attention. Even as young adults move out and live on their own, they had (have?) to hide their self-gratification or relational pleasuring intentions from their attendants and from other caring adults in their life. Perhaps we should advocate a new branch of science: I suggest we call it *Alternative and Augmentative Sexual Expression.* I propose that its goal be to help people with physical (and other) disabilities to experience love and interpersonal relationships to the fullest, whatever their orientation. Or maybe, and more practically, we should start circulating these stories on the web so that other people can share the laughs and embarrassments and learn.

Parents

Children and young adults with disabilities are in many ways much more dependent on their parents and on other adults (attendants, nurses, professionals) than able-bodied teenagers and young adults. This dependence is in some instances a matter of life and death. I have probably told the story of the teenager who started to lose weight at an alarming rate. After much testing, medical and psychological investigation revealed that she intentionally stopped eating because she did not dare to continue to grow, for fear that her mother would not be able to lift her in and out of her

chair anymore. Imagine that you are dependent on one or two people for moving from one place to another, being lifted from one surface to another, being fed and offered a drink, for voiding, breathing, reconnecting the ventilator hose, suctioning and caring for bedsores, colds, infections, and inflammations of all types. Would you not be extremely careful not to set these people against you through acts or revelations that you (rightfully) fear would upset them?

Pros and Cons

The Hetrick-Martin Institute recommends that (able-bodied) gay and lesbian teens not tell their own parents that they are gay because of the danger of being thrown out of the house and/or cut off financially (Marcus, 1991 p. 37). Some people never come out. According to Marcus (p. 41), three of the main reasons for not coming out are: necessity, fear, or simply because the person prefers not to share this part of their lives with others. Not coming out *of necessity*, occurs when persons believe that they will lose their jobs or parental support. *Fear* is often involved in the decision not to come out, *fear* of being rejected, *fear* of losing custody of their children, or *fear* of physical violence at the hands of others. According to Marcus (p. 41), much of the fear is justified by the horror stories we have heard, read, and experienced personally. Nevertheless, in his chapter on *Coming out Going Public,* Marcus answers the question "What is it like to come out of the closet?" as follows:

> "The experience may have been painful, traumatic, frightening and overwhelming, but almost none of the people I've spoken with have said that they regret living life free of the closet." (p. 46)

Not every coming out is as flamboyant, public and anticlimactic as the one Ellen DeGeneris went through in her TV series. Every coming out is more a long term process than a single dramatic event, because one always meets new people and has to make the coming out decision over and over again. For most teenagers and young adults coming out means a dramatic and serious change in their lives and in their relations with others. Some of these changes are self-selected but many are imposed or incurred as a consequence of the fact that the newly confessed gay or lesbian is perceived to be different from the people who were their friends before they came out. Parental reactions may run the gamut from scorn, disavowal, denial, upset, anger, loss, and incomprehension to another range of more accepting or understanding reactions.

Risking your status as child, employee, friend, parent

Parental reactions are the first hurdle for people with disabilities, especially for those who are being cared for by their parents. Needless to say, it is also difficult for the parents. I am not denying this but I think that the predicament of the child who realizes that he or she has a different sexual orientation is more difficult by far. Family, brothers and sisters, aunts, uncles, friends, community members and other institutions all will have their reactions to a person's coming out. Losing all or the majority of your friends is a big problem for a teenager, perhaps more so since it is sometimes difficult for people with disabilities to build a circle of friends. On the other hand, coming out will be the kind of life-change event that will itself lead to the rebuilding of a social life with new friends and new support structures. Other societal institutions, much like parents, can react along the same continuum — from guardedly positive through empathy to subtly shunning then outright rejection. If you belong to a church with an understanding pastor and community you are very lucky. A more conservative or constricted shepherd and flock may actually shun the offending member, although I would hope that this does not happen anymore.

School, work and other corners of society are perhaps easier to navigate, although I am not sure if this is true in general and everywhere. I know that in my high school years in a smallish (Dutch) community it was not easy for people to come out and for their to accept them. At university it was much easier for gays and lesbians to be themselves and I did not witness any discrimination. I hope that this attitude by now has taken over high schools and colleges everywhere.

Resources

Its taken many years for gay bars to be public knowledge. What about gay bars for people with disabilities? Do they exist? Or, are gay bars accessible? Where does one turn to to find answers? Internet? I did a search on AltaVista using the phrase: Coming Out Resources. This resulted in more than 146,000 sources. 30,000 of those related to coming out directly. One of the more frequent entries were coming out stories including separate Deaf Queer Coming Out Stories. In the documents I looked at, there were no Disabled Queer Coming Out Stories. The function of these stories like the more public outings of more famous people is not just the world-wide announcement of one's status. It is also the sharing of the experience and the learning about other people's experiences. This practice of publishing one's story on the web is something that could be very beneficial for people with disabilities. The ways in which they have solved problems that are not typical can be used by other people who find themselves in the same predicament. §

(References are on page 6)

See What We Say

by Barbara Collier (1998)

SHIRLEY McNAUGHTON

See What We Say is a must for those who have their augmentative and alternative communication systems (communication displays and/or devices) in place, live in a community setting and want to participate in community activities. It offers AAC users and those who interact with them "vocabulary and tips" pertaining to a wealth of topics.

The section headings demonstrate the scope of the book:

- Upgrading your vocabulary
- Directing personal care
- Participating at your own case conference
- Interviewing service providers
- Communicating about your AAC system
- Communicating about seating
- Transportation
- Advocacy
- Banking and finances
- Grocery shopping
- Eating out
- Learning a new skill
- Meeting new people
- Using the telephone
- Health and safety
- Participating at a conference
- Sexuality
- When people don't understand your message
- Conversational routines
- Death and bereavement
- Legal vocabulary
- General Resources

The book's author, Barbara Collier, is a speech language pathologist who has worked for over 18 years in augmentative and alternative communication. After many years as an AAC consultant with the pediatric Augmentative Communication Service at the Hugh MacMillan Rehabilitation Centre, Barbara became the director of the Adult Augmentative Communication Service, located in the same centre. In 1996, with the closing of the adult service, Barbara began work as a private consultant. In this role, she has had the opportunity to interact with many AAC consumers and their attendants in their home settings. She has become increasingly aware of the limitations imposed upon AAC users due to the lack of appropriate vocabulary being available to them. Thanks to a grant from The Trillium Foundation, Ontario, Barbara has been able to produce a valuable reference book. In it she responds to the needs of both consumers and their caregivers. The strong involvement by experienced AAC users and service providers in the topics, tips and suggested vocabulary is evident throughout!

See What We Say does much more than provide vocabulary and tips, however. It offers an approach to decision-making regarding vocabulary and it stimulates ideas about the AAC user's participation in varied situations. The layout of the book is excellent, with each topic containing vocabulary suggestions, along with tips relating to communication relating to that topic. There is advice regarding the organization of vocabulary and practice in using the vocabulary.

Since the theme for this issue of Communicating Together is sexuality, it is being selected to demonstrate the approach taken. All the sections, however, deserve attention!

The vocabulary suggestions relating to sexuality include: (a) general items such as sex with and without consent, privacy, no privacy and (b) categories like body parts, reproduction and health, birth control, sexual orientation, sexual arousal, feelings, relationships, abuse. Overall there are over 140 suggested vocabulary items relating to sexuality. The books, End the Silence by Pip Farrar and Being Sexual by David Hinsburger and Susan Ludwig are referenced. Tips relating to visiting the doctor and the individual's right to accurate information are given.

See What We Say reflects a very valuable approach, one in which AAC users are provided with information accompanied by choices. It gives individuals the opportunity to enhance their communication and their well being through broadening the types of situations in which they can partipate and extending what they can say in these situations.

See What We Say can be ordered from:

Harmony Place Support Services
132 Railside Road, Unit #6
Toronto, Ontario M3A 1A3
Phone: 416-510-3351
Fax: 416-510-0824
email <whaans@interhop.net>

The regular price is $44.00 Cdn. (including tax and shipping and handling). The AAC user price is $29.00 Cdn. (including tax and shipping and handling). Cheques should be made payable to Harmony Place Support Services.

Postscript

Since *See What We Say* was written for those who already have a communication system in place, the advice given is "Represent your vocabulary in a way that makes sense to you." In thinking about *what makes sense* while considering sexuality symbols, AAC users may wish to read the Symbol Talk relating to Vocabulary and Sexuality, in **Communicating Together**, March, 1992. Copies are available from **Communicating Together**, free upon request. It was written to help evaluate the *manner* in which sexuality vocabulary was represented and emphasized the following: (1) the need for the symbols to portray accurate and relevant information, (2) the need to respond to the user's feelings regarding privacy, (3) the need to protect the dignity of the user, and (4) the need to consider the reactions of others.

Write for a free copy of *Vocabulary and Sexuality* by Shirley McNaughton as a useful complement to *See What We Say* in the area of sexuality.

For Bliss users, there is another valuable series of books:

Being Sexual by David Hinsburger and Susan Ludwig. For information contact: SIECCAN, 850 Coxwell, Ave., Toronto, Ontario M4C 5R1.

§

End the Silence

Preventing the Sexual Assault of Women with Communication Disorders; Developing a Community Response.

by Pip Farrar (1996)

BARBARA COLLIER

Pip Farrar knows the issues and risks for sexual assault for women who use AAC. She clearly states that women who use AAC often rely on others to include vocabulary about sexuality in their communication devices. Yet she notes that this vocabulary is often omitted. Without it, she says, education in, and discussion of personal safety, healthy sexuality, and sexual assault cannot occur. Women who cannot communicate cannot prevent or report assault, cannot access the justice system and are unable to receive counselling. In dealing with the issues to prevent sexual assault and abuse against women who use AAC, Farrar presents strategies to develop effective communication, healthy sexuality, access to the legal system and help with counselling.

Written for the *Technical Resource Centre* in Calgary, the manual is for women and children who use AAC, their parents and guardians, caregivers, health professionals, counselors, justice system officials, friends and educators. While the author acknowledges that boys and men are also subject to sexual assault she has chosen to focus on the experiences of women. The author asks that the manual be used to promote the safety of people with disabilities by increasing communication between agencies and individuals to build appropriate support networks.

The manual deals head on with this sensitive subject in a clear and honest manner. By using real life stories throughout the text, Farrar demonstrates that she intimately understands the issues faced by women who use AAC. She addresses the AAC user directly throughout the manual and presents complex issues in a language which can be understood by a wide range of readers. The manual is written in large, easy to read print. It is beautifully illustrated in a spiral bound format which holds it flat during reading and makes it easier for people with disabilities to turn the pages.

Farrar explains the purpose of the manual. She writes that it is about ending the silences that prevent too many women and children with communication disabilities from:

- developing and meeting their personal needs healthily and to the full;
- defending themselves against sexual assault and sexual abuse;
- reporting sexual assault and abuse and from seeing justice done if they have been assaulted or abused.

In the introduction, the author notes that the risks of sexual assault for people with disabilities is higher than for people in the general population. The level of risk depends on the definition of sexual abused used. For example, if sexual abuse is defined as any unwanted sexual behavior the risk may be twice as high for people with disabilities than in the general population. If the definition of sexual abuse is restricted to requiring sexual contact the risk for people with disabilities may be five or more times higher than the general population (Sobsey 1994). The risk appears to increase with the amount of disability experienced (Sobsey & Varnhagen 1988). There are no studies that have looked specifically at the risks for AAC users. However, the author notes that the best victim is the one who cannot tell, so it seems likely that people with disabilities who are also communicatively impaired are at a very high risk.

Chapter 1 introduces the reader to the topic of healthy sexuality. It deals with issues such as self image, the role of sexuality in society, gender roles and stereotypes, and sexual discrimination. It outlines helpful hints for developing positive self esteem, the rights of people with disabilities and includes a healthy sexuality and disability quiz.

Chapter 2 is about developing and using specific personal and interpersonal skills for healthy sexuality. It discusses feelings, values, choices and consequences, assertiveness and negotiation skills. In a section on relationships, it deals with healthy and unhealthy sexual relationships, friendships, dating, love, marriage and parenting.

Chapter 3 provides a well illustrated overview of the anatomy and physiology of reproductive body parts. It discusses topics such as sexual behavior and sexual response (e.g., privacy, sexual arousal, shared sexual behavior, sexual adaptations to functional problems etc.) and sexual health (e.g., personal hygiene, reproductive health, contraceptive choice, etc.). Throughout this chapter there is vocabulary which is essential for AAC users to have on their displays or in their communication devices.

Chapter 4 explains sexual assault (e.g., why it happens; what kind of people are abusers; what abusers might say; myths and facts about sexual abuse and protecting yourself from sexual assault). It provides advice for AAC users who have been sexually assaulted (e.g., when the offender is known; if the AAC user is a teenager; if the AAC user is a lesbian etc.). It discusses the fears about reporting sexual abuse for women who use AAC; what they can do if they were assaulted in the past and what to do if they are assaulted in the future. For a woman who has been sexually assaulted it outlines her rights and the process involved in getting medical help, accessing the law, reporting to the police, and waiting to go to court.

Chapter 5 is for parents. It highlights the importance of providing vocabulary and education on sexuality and abuse. In addressing parents, Farrar writes "Without the vocabulary your daughter is vulnerable. Without education and accurate information she cannot make informed choices about sexual behaviors". This chapter goes on to discuss parents' concerns, their roles and the issues they need to consider when talking about and teaching healthy sexuality (e.g., verbal ability, communication, getting accurate information, putting vocabulary on AAC systems, modeling and practicing required skills and getting the support they need). There are sections on responding to a disclosure of sexual assault; legal rights and procedures; being an advocate; preventing sexual assault and develop a contingency plan in the event that their daughter is sexually assaulted.

Chapter 6 is on understanding the role of a guardian. It explains Alberta's guardianship law which provides guidelines for people who need help with decision-making. It explains the extent and limits to decision making and the responsibilities and role of guardians.

Chapter 7 is specifically written for health care professionals. It addresses issues such as providing sexual and reproductive care; communicating with an AAC user; providing medical help after a sexual assault and procedural issues for emergency departments.

Chapter 8 is for police. It contains sections on attitudes, background information on women who use AAC; facts about disabilities and sexuality; Charter rights of people with disabilities; guidelines for responding to a complaint, and how to have successful interviews with AAC users who have developmental disabilities.

Chapter 9 is for caregivers, teachers, vocational and residential service providers. Topics include issues faced by these service providers; preventative measures; roles and responsibilities.

Chapter 10 is for rehabilitation therapists. Specifically, it addresses the roles of the both the occupational therapist and the speech-language pathologist in teaching healthy sexuality. It provides suggestions for assessment, prescription and development of AAC systems, and vocabulary selection on sexuality. It includes sample picture displays on issues relating to sexuality and sexual assault.

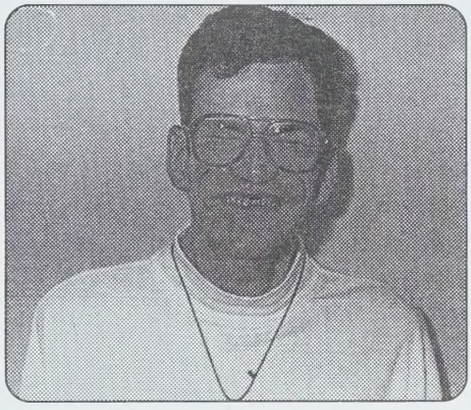
Finally, there is an extensive listing of support services for healthy sexuality, an inventory of videotapes, magazines and books, and a bibliography.

End the Silence is a must-have resource. It recognizes that an entire community response is required to address and prevent the sexual assault of women with communication disorders. Farrar must be commended on her significant contribution to the lives of women who use AAC. Our work is to get the word out, tell AAC users and their families about this resource, share a copy with our local police station, give it to our hospitals and emergency departments, make it available to social workers, justice system officers, health professionals, counselors and others.

Available free from:
Technical Resource Centre,
200, 1201-5 Street S.W.
Calgary, Alberta T2R OY6
Tel. 403-262-9445 Fax. 403-262-4539 §

Society's Compass

PAUL MARSHALL



Paul Marshall

Have you ever wondered where north is? Has our society asked the same question? We are just under two years before the beginning of a brand new century, a century that I am sure will bring us many new and amazing breakthroughs in every aspect of life. In many ways, we are at the horizon of this new century where the sun is just about to break upon the night sky. What we do today will effect and have a great impact on how we design and live in the new era.

Sexuality is the fearful and the untouched topic that makes each one of us uneasy. I was thinking "How can I get out of putting a column together?" when we as co-editors started to discuss this issue. This issue has the potential to change our years ahead, negatively or positively. I don't agree with the worldly view today that everything is OK, "you can do whatever you want." It seems today we are an "everything goes" society, and it is wrong — plain and simple. Society has to set some limits, otherwise we will have a "limitless society".

I personally hold that sexuality is not a "free for all" issue. Thinking back to when I volunteered at an inner-city street kids ministry, this had extremely negative impacts upon lives. It was a "free for all" — wide open when it came to having sex with whomever. I will disagree with anyone who says that having sex outside of marriage bonds does not have lasting public and individual implications. I know of many street kids who died of Aids or had babies with three or four girls, with the "males" having no sense of responsibility — they just went on their way.

I can think of three ways of looking at sexuality. There are likely more than my three views but I will stick with what comes to mind. They are the biblical view, the world view and the self view. The main biblical view is that sex has to be based in a marriage bond between a husband and wife. There is no other alternative when the Bible talks on this topic. Now, we might turn up our noses and say that the Bible is outdated. When we look at the old testament, we see how people tried to rule and dismiss this one commandment and their lives were much different and more stressful. The Christian view of having sexual relationships has been the main backbone of many of the western cultures — that one man and one woman would become one through a marriage bond.

The world view changes. It ebbs and flows with the different generations' views on this topic. Our different cultures put different values upon sexual limitations. We seem to be in a period of time when anything goes. It is OK. I will just turn my head and you can do whatever you want. My question is: "Is this the right viewpoint that we should take?" I see more and more people who just don't take a stand on anything today. As you might realize now, I have my concerns of what I call "the world view" on sexuality.

The self view depends largely on how the world views sexuality. If our kids see that society seem to OK doing whatever we want, then they will do whatever they want. They will likely widen the gap between the Biblical view and what I call the world view. This will keep going until something changes the flow.

When it comes to sexuality, I probably have two strikes going against me. First I have to use another form to communicate that is not the "normal" way of talking. This puts up "mental barricades" to engaging in and exploring relationships. These mental barricades do not mean that it is not possible to have relationships. There are many nonspeaking individuals who are in relationships and doing well.

My second strike is my deep belief in the Bible. This narrows my options when it comes to entering into any relationship. Marriage is not a big deal to me. I like my life the way it is. I am allowed to spend my days doing what I feel is important to me. I know I am spoiled because in many ways my time is wide open to help with many things. If a relationship comes into my life, it would be wonderful. If it doesn't, it is not the end of the world.

If I didn't have a disability, would I be in a relationship? Maybe yes, maybe no. As I said before, disability is only skin deep. With sexuality, we may be putting too much weight upon the disability and not enough upon the beauty that lies within or upon personal choice.

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Communicating Together was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn.* Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

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Typesetting & Printing:
Central Printing Services, Guelph, Ontario.

Subscription Rates per Year:

Canadian	- $25.00 Cdn;
U.S.	- $23.00 U.S;
Outside North America	- $30.00 Cdn.

ISAAC Members' Rates

Canadian	- $20.00 Cdn
U.S.	- $17.00 U.S.
Outside North America	- $26.00 Cdn.

For **ComTog-OnLine**, add $5.00 to the above rates.

Direct correspondence regarding subscriptions, articles, advertising, subscription support, address changes and bulk mailing to:

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Second Class Mail Registration No.7093
GST Registration No. R130220619
ISSN No. 822-0638

Cover:
The cover shows Anne Abbott and Rob Warrendon on their wedding day.

The publisher offers **Communicating Together** as a vehicle for editors, associate editors and contributing authors to present their perspectives on augmentative and alternative communication. The views expressed are not necessarily those of the publisher although the human interest, consumer involvement and international perspective are.

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Communicating Together is an affiliated publication of the International Society for Augmentative and Alternative Communication (ISAAC).